TESTIMONY BILL #5499 3/16/2012

Dear Madame Chair and Distinguished Committee Members:

Today I ask you to think for a moment about how our patients die. If death arrived like Sandburg's fog "...on little cat feet...on silent haunches and then moves on.' then patients could die quietly in their beds at home. But many struggle in the throes of death, grappling--physically, emotionally, spiritually, and psychologically, and it is for those individuals and their caregivers that we have the level of hospice care we call 'inpatient.'

In the last days of life, the intensity of symptoms such as escalating pain or delirium can cause unbearable caregiver distress, despair, confusion, and anger. A poor understanding of the dying process, the uses of opioids and sedatives as well as the need to make funeral arrangements and to begin to think about life without the loved one can create a state of disequilibrium that often compromises family coping. A transition to inpatient hospice at this moment of crisis and uncertainty necessitates an interdisciplinary team surround the family with expertise and support, to be present as 'first responders' to attend to the acute needs of both patient and family, to comfort, to educate, to allay anxiety and diffuse conflict anger.

In December of 2010, an 80-year-old with end-stage dementia male received care at CT Hospice Inpatient. He was experiencing increasing agitation called terminal restlessness, a state of pre-death delirium common in moribund patients and considered a palliative care emergency

- At daily rounds the IDT of physicians, APRN, pharmacists, nurses and social workers examined possible etiologies of restlessness, including work up for UTI, medication review and evaluation of lab work and review of environmental factors
- 31 references to agitation were noted on chart review, including 'wandering, shaking of bed rails, climbing OOB and stripping.'
- Multiple notes by nursing, social work, pharmacy and medicine recorded ongoing support and education to the wife regarding safe feeding as evidence of dysphagia and aspiration were present
- The patient died on day 22 with respiratory congestion having received multiple doses of scopolamine and Dilaudid to relieve respiratory distress
- Such refractory restlessness required ongoing efforts at medication management made by the APRN in consultation with pharmacy. Total medications given were 360; as needed medications for agitation were 40 (in addition to trials of scheduled Haldol, benzodiazepines, atypical antipsychotics and finally Thorazine for severe agitation)

We at CT. Hospice are deeply distressed that the proposed changes to inpatient regulations threaten quality of care to the most seriously ill patients in our state by implementing minimum standards that pertain directly to nursing and medical staffing, provision of pharmacy services, and the elimination of an assembled, ever-ready, complete and onsite interdisciplinary team which performs initial assessments immediately upon admission with medication review and oversight and development of an initial interdisciplinary plan of care. Proposed regulations beg the question of how facilities with 'sufficient' staffing will adjust to changing levels of acuity? Will agency nurses be scheduled or home care nurses be called in to work? Who would have the expertise to respond to the crisis of a an elderly patient with dementia or of a 51 year old with cholangiocarcinoma? This young man with intractable pain and restlessness required daily and more frequent changes in his medications which included high-dose intravenous methadone and morphine and both Phenobarbital and pentobarbital. Would off-site 'consultative' pharmacy services be adequate to oversee the plan of care to assure optimally dosed and safely and effectively administered medications? Would those medications be readily available for this patient's comfort as his symptoms escalated exponentially day by day and hour by hour? Without the direct involvement of a truly skilled interdisciplinary team, this patient would have suffered inexorably and most certainly have been transferred to a hospital setting.

While it is difficult to quantify the time an RN may spend at the bedside in providing hands-on care with bathing and hygiene and performing physical assessment or in medicating for the constellation of symptoms that crescendo over the course of a day, consider that under the present staffing ratios, a Ct Hospice RN may have an assignment with *one, two or even three such seriously ill patients* as described above, all requiring intensive intervention due to

- Terminal Restlessness
- Seizure management for patients with brain metastasis, brain tumors, renal failure and end-stage dementia and stroke
- The disfigurement and dysfunction, pain and hemorrhage associated with head and neck, gynecologic and gastrointestinal tumors
- The respiratory distress of end-stage cardiac and respiratory illness
- The total dependence of those with ALS and other neurological disease as well as those with brain tumors
- The heart-wrenching challenges of pediatric and adolescent cases
-

The issue at hand is not access to care: we all want hospice patients in our state to have access to quality inpatient care that is close to home and maintains relationships with established providers. **The key word is *quality:*** so we emphasize that we are here today again asking for a guarantee that quality is assured by stipulated staffing ratios and onsite pharmacy and medical services.

Because we know how challenging the care of our inpatient population is, CT. Hospice educates every newly hired RN, and every nursing assistant in two Fellowships funded by the Norma Pfriem Foundation. Since the inception of the Nursing Fellowship in 2005 approximately 40 RNs have been credentialed by national exam in hospice and palliative nursing under the Hospice and Palliative Nursing Association.

The current regulations offer the most effective, timely, safe and holistic experience for the hospice family and ***assure our shared mission to provide comfort and dignity, and support the ethical tenet to do no harm.*** For 35 years Connecticut has served as a model of excellence to the nation: why now lower the bar by changing the existing regulations for inpatient hospice care?